

**Policy for the Disclosure of Confidential Public Health Records
#ES 06-13-002**

Effective Date: 8/1/2014

I. PURPOSE AND SCOPE OF POLICY

The Iowa Department of Public Health (IDPH) is governed by Iowa's Open Records law and generally provides public access to all records it collects under IDPH legal authority (Iowa Code chapter 22). In addition, IDPH is committed to providing information, data, and records to the public and the media to promote and protect the health of the population.

However, Iowa law also provides that certain information, data, and records collected under IDPH legal authority are confidential and may not be disclosed to the public. For purposes of this Policy, a "confidential public health record" includes a record, certificate, report, data, dataset, or information which is confidential under federal or state law.

The purpose of this policy is to outline the legal status of confidential public health records, and to provide guidance to IDPH employees regarding the disclosure of confidential public health records.

These guidelines are generally applicable to all confidential public health records collected under the legal authority of the IDPH. However, certain confidential public health records are governed by additional regulations as well as specific exemptions. Additional specific guidelines for the release of reportable disease information can be found in the *Policy for Disclosure of Reportable Disease Information* on the IDPH Center for Acute Disease Epidemiology website.

II. CERTAIN PERSONALLY IDENTIFIABLE INFORMATION IS CONFIDENTIAL

As a general rule, public health records which contain personally identifiable information of a health-related nature are confidential under Iowa Law.

For example, IDPH is required by law to generally maintain the confidentiality of the following records:

1. Hospital records, medical records, and professional counselor records of the condition, diagnosis, care, or treatment of a patient. Iowa Code § 22.7(2).
2. Personal information in confidential personnel records. Iowa Code § 22.7(11).
3. Records pertaining to participants in the gambling treatment program. Iowa Code § 22.7(35).
4. Medical examiner records and reports, including preliminary reports, investigative reports, and autopsy reports. Iowa Code § 22.7(41).
5. Personally identifiable medical information provided for the purpose of studies to reduce morbidity or mortality. Iowa Code §§ 135.40, 135.41.
6. Social security numbers. 42 USC 405(c)(2)(C)(viii)
7. Personally identifiable information and business identity related to a reportable disease or condition. Iowa Code § 139A.3; Iowa Code §§ 139A.30 - 32.
8. Personally identifiable information related to HIV/AIDS. These reports are maintained as "strictly confidential medical information" and specific provisions prevent disclosure of this

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- information except under very limited circumstances. Iowa Code §§ 141A.6, 141A.9.
9. Personally identifiable information contained in IDPH registries, including the Statewide Trauma Registry, Immunization Registry, Central Registry for Brain or Spinal Cord Injuries, and Congenital and Inherited Disorder Registry. Iowa Code §§ 147A.25, 147A.26; 641 IAC 136.2(5); Iowa Code section 22.7(2); 641 IAC 7.12; Iowa Code § 135.22; Iowa Code § 136A.7.
 10. Professional licensing board information, including EMS. All complaint files, investigative files, investigative reports, and all other investigative information of a licensing board or its employees or agents which relates to licensee discipline are confidential. Iowa Code § 272C.6(4). However, the statement of charges, notice of hearing, and the final decision of a board, whether after hearing or through a settlement agreement, are public.
 11. Vital statistics records. Iowa Code § 144.43.
 12. Substance abuse program patient information and some licensing information. Iowa Code § 125.37; Iowa Code sections 22.7(2), 22.7(18), or 125.37; 641 IAC 155.16(5).
 13. Iowa Domestic Abuse Death Review Team and Iowa Child Death Review Team records pertaining to a specific death. Iowa Code § 135.111; Iowa Code § 135.43(3).
 14. Records which contain identifiable information related to a child's newborn hearing screening, rescreening, and diagnostic audiologic assessment. 641 IAC 3.10.
 15. Perinatal program surveys and reports. Iowa Code § 135.11(28).
 16. All medical, health and nutrition information collected regarding WIC program participants. 7 CFR 246, Iowa Code section 22.7(2), 641 IAC 73.7(7).

III. STATISTICAL, AGGREGATE OR TABULAR DATA MAY BE RELEASED IN ACCORDANCE WITH THE FOLLOWING GUIDELINES

IDPH is generally authorized to release data from a confidential public health record to the public so long as such release could not result in the identification of a person. Identifiable information (or identifiers) includes information that can be used to directly establish the identity of a person, such as a name, address, or unique identifying number. Identifiable information also includes information that can be used to indirectly establish the identity of a person by linking such information or data with external information that allows for identification of the person, such as obituaries, newspaper articles, or information on public websites.

IDPH may therefore generally release information or data in an aggregate or a tabular format.

The determination of whether the release of aggregate information or tabular data would result in the identification of a person may be straightforward.

Example: IDPH can report that the state experienced 29,066 deaths in 2014 without violating confidentiality provisions.

Example: IDPH cannot report that a 58 year old African American female residing in Adams County died from a stroke, if there is only one 58 year old African American female residing in Adams County, as such release would result in identification of this individual.

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Oftentimes, the determination of whether the release of information is consistent with confidentiality restrictions is complex and may require additional analysis and consultation with these guidelines including the department's legal counsel and data use advisors.

In determining whether release of aggregate information or tabular data would result in the identification of a person, IDPH will generally follow the Centers for Disease Control and Prevention's (CDC) scientifically acceptable principles for confidentiality protection. IDPH has relied upon selected guidelines from the CDC's Staff Manual on Confidentiality, the National Center for Health Statistics Staff Manual on Confidentiality, and the CDC-CSTE Intergovernmental Data Release Guidelines Working Group Report: CDC-ATSDR Data Release Guidelines and Procedures for Re-Release of State-Provided Data, in preparing this policy. In addition, IDPH relied in part upon the Washington State Health Department's Guidelines for Working with Small Numbers in developing this policy. These sources can be found on agency specific web-sites.

In general, the following guidelines apply to the release of confidential public health records by IDPH:

Please note that all examples used in this policy are fictional.

Disclosure of Personal Identifiers Prohibited.

- IDPH shall not release information which directly identifies a person named in a confidential public health record, including name, address, telephone number, social security number, medical record number, exact date of subject's birth, or other direct identifiers.

***Example:** On March 1, 2014, a physician reports to IDPH that Jane Doe, medical record number 7654321, a female living at 100 Main Street in Cedar Rapids, Iowa has been diagnosed with HIV. Jane Doe's name, medical number, and address are confidential and cannot be released by the health department. However, her case will be added to the total number of HIV cases in the state for the year, and that total number may be released.*

- IDPH shall not knowingly release information which can be used to indirectly establish the identity of a person named in a confidential public health record by the linking of the released information or data with external information which allows for identification of such person.

***Example A:** Bobby Smith, a 2 month baby boy from Ringgold County, dies of a congenital heart defect on January 30, 2014. An obituary in the local paper states his age at death and the date of his death. If IDPH releases information that a 2 month baby from Ringgold County died on January 30th from a congenital heart defect, that information could easily be linked with the obituary to establish his identity. For this reason, IDPH and local boards of health and health departments should not release all of these identifiers about Bobby Smith, but instead should broaden one or more of the identifiers to prevent the identification of Bobby Smith. See how to broaden identifiers below.*

Certain media outlets have expressed an interest in receiving information about (1) county of residence, (2) age range in the general categories of child, young adult, adult, or elderly, (3) time frame identifier, and (4) health status. In some cases it will be appropriate to release information from all four categories as requested. However, one or more identifiers may need to be broadened to ensure that the information provided cannot be linked with external information to allow for identification of such person. **See section IV concerning release of data to the media.**

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Example A (continued): The county of residence could be broadened so that the release provides that a child in Southwest Iowa died of a congenital heart defect on January 30, 2014. **See section IV concerning release of data to the media.**

Example A (continued): The time frame identified could be broadened, so that the release provides that a child from Ringgold County died of a congenital heart defect in 2009 - 2014. **See section IV concerning release of data to the media.**

Example B: A seven year old black male in Taylor County has sickle cell anemia. This type of anemia is most commonly found in African-Americans. Since there are few African-Americans in Taylor County, IDPH and local boards of health and health departments should not publicly disclose that a seven year old in Taylor County has sickle cell anemia, as doing so could lead to the identification of the child. **See section IV concerning release of data to the media.**

Example B (continued): The age group and gender could be broadened so that the release provides that a child aged 0-17 years in Taylor County has sickle cell anemia. **See section IV concerning release of data to the media.**

- IDPH shall not respond to inquiries about a confidential public health record which include direct personal identifiers in a manner which confirms an inquiry.

Example C: An employer contacts IDPH concerned about the health status of their employee Jane Smith. When told that this is confidential information; he then asks whether his business has an employee enrolled in a gambling treatment program. IDPH cannot release any information regarding the health status of any individual employee to the employer, nor can IDPH confirm if an employee participates in any treatment programs.

Example D: A soccer coach at the Prairie Ridge Recreation Center wants to know if the members of his team have received their influenza vaccines. IDPH and local boards of health and health departments cannot disclose directly to the coach, any information that would confirm if any of the soccer players had received their influenza vaccines.

Aggregate Data Values.

- When releasing information from confidential public health records, IDPH must expand or broaden the identifier fields as needed in order to prevent identification. Common methods for preventing identification include:
 - Redacting (removing) variables which directly identify a person, including name, address, telephone number, social security number, medical record number, exact date of case-patient's birth, or other direct identifiers.
 - Collapsing continuous/interval data (e.g., age, date of occurrence) into broad categories.

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- o Collapsing ordinal data (e.g., location, geography) into broad categories.
- o Suppressing of small numbers to ensure confidentiality

Definitions and Examples:

A numerator is the number on top and a denominator is the number on the bottom of a ratio. For example, if 13 of 62 people who attended a church supper became ill, 13 is the numerator, and 62 is the denominator.

A line listing is a row of data in which only one piece of information per category is available. For example, the number of cases per county is available in the line listing of reportable diseases in Iowa. (See example at <http://www.idph.state.ia.us/IDPHChannelsService/file.ashx?file=1F4162C0-DDEC-4188-86C5-3330F859183A>).

A table refers to the arrangement of descriptive or identifying data (for example age, gender, or race) in columns (vertical) and lines (horizontal), with the intersection of a column and a line referred to as a “cell”, where several pieces of information are available per number. For example, the following hypothetical table of *Emergency Department Visits for Heart Attacks* in Johnson County includes age and gender. This sometimes referred to as “cross-tabs” when two pieces of identifying information (e.g., age and gender) are used to arrange data in a table.

Example:

<i>Emergency Department Visits for Heart Attacks in Johnson County</i>					
Gender	Age 40-49	Age 50-59	Age 60-69	Age 70+	Total
Female	1	3	4	6	14
Male	2	5	11	15	33
Total	3	8	15	21	47

Use Numerator/Cell Size Rules for Data Aggregation or Suppression.

- When releasing information from confidential public health records, IDPH should use numerator/cell size rules to either guide selection of groupings of aggregated data values, or if aggregation is insufficient, to suppress release of certain cells in a table. **IDPH should not release data if the numerator cell size is five or fewer: numerator cell size counts of one, two, three, four, and five should not generally be disclosed.** A count of no cases or events in the cell is not a threat to confidentiality and may be released, but a count of one, two, three, four, or five cases or events is a threat to confidentiality and should not be released.

Example: A local health department is asked for information about teen pregnancy by age. The county has had one 14 year old, two 15 year old, two 16 year old, and four 17 year old teen pregnancies. Because there are fewer than 5 in each cell, the county should collapse the individual ages into one cell of teen pregnancies for seventeen years of age and under, so the release of information would state the county has had nine teen pregnancies of 17 years of age or younger (as long as denominator rules apply).

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If data are released in a line listing, then the numerator suppression rules do not apply. The numerator suppression rules do not apply because only a single piece of information per category is being released in a line listing, therefore potential identification is not possible.

Example: The number of trauma service cases in Iowa by year may be released.

Trauma service cases in Iowa				
	2009	2010	2011	2012
Trauma service cases	2,611	2,917	3,078	3,270

If data are released in table format, the following additional guidance should be followed:

- In no table should all cases of any line or column be found in a single cell.
- In no table should the total figure for a line or column of a cross-tabulation be five or fewer.
- In no table should it be possible to identify a person through subtraction or other calculation from the table or a combination of tables.
- Data released by IDPH or local boards of health and health departments should not permit identification of a person when used in combination with other external data.

Example: The table below shows all of the *Salmonella* cases in Polk County. The table cannot be released to the public because there are single cell counts below 6. All counts below 6 should be suppressed.

Salmonella cases in Polk County						
Race	Age 0-17	Age 18-40	Age 41-60	Age 61-80	Age 81+	Total
White	22	16	13	11	10	72
Black	11	5	4	6	8	34
Asian	2	1	2	1	3	9
Pacific Islander	0	0	0	0	4	4
Total	35	22	19	18	25	121

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Example: The table has been revised for numerator suppression. All counts, both single cell counts and total counts, of 5 or fewer have been replaced using an "S". Cell values may not be identified by simple calculations. The table below can be released to the public.

Salmonella cases in Polk County						
Race	Age 0-17	Age 18-40	Age 41-60	Age 61-80	Age 81+	Total
White	22	16	13	11	10	72
Black	11	S	S	6	8	34
Asian	S	S	S	S	S	9
Pacific Islander	S	S	S	S	S	6
Total	35	22	19	18	25	121

S= suppressed number

Use Denominator/Population Size Rules for Data Aggregation or Suppression.

- When releasing information from confidential public health records, IDPH should use denominator/population size rules to either guide selection of groupings of aggregated data values, or if aggregation is insufficient, to suppress release of certain cells in a table. Prior to disseminating the information, IDPH should consider the size of the denominator (the population size represented in each cell of a table). Data should not be released if the total population from which the data are drawn is less than 100. This is based on the premise of a population size sufficiently large enough that no subcell of the variables contained in the data would be expected to be smaller than 5. Generally, tabular data based on denominations greater than 300 persons per cell present *minimal* risk for personal identification. Caution should be exercised if the cell's population size is between 100 and 300, and release should not occur if the population is less than 100.

Example: Assume there is an outbreak of Giardiasis in Ayrshire, Iowa, population 202, where seven ten year olds were infected with this disease. Public health authorities should not release that seven ten year old children in Ayrshire were infected with Giardia, because even though the numerator/cell size is over five, the denominator/population size is below 300. Because there are only a small number of ten year old children in this town, such a release may in effect be identifying every one of these children as potentially infected with Giardia. The release should instead provide the relevant information for the county.

Summary

- IDPH shall not release information which directly identifies a person named in a confidential public health record, nor respond to inquiries in a manner that confirms the identity of a person.
- IDPH should generally not report cells with counts of five or fewer.
- IDPH should be cautious when reporting rates or ratios based on denominators less than 300 and should not disclose data based on denominators less than 100.
- IDPH should be cautious when reporting a specific disease in a minority population if a high proportion of the minority population has this disease, or if the disease is primarily

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found in a specific population.

- When producing tables, IDPH should be careful that users cannot derive confidential information through a process of subtraction.

IV. RELEASE OF DATA TO THE MEDIA

An important mission of public health is informing the public through the media about issues which impact the public's health. IDPH staff should collaborate with its public information officer and other appropriate staff to determine the content, nature, and scope of information to be released to the media.

When releasing demographic information regarding specific case-patients to the media, the following guidelines should generally be followed. In certain situations this level of detail may not be appropriate for release as described in this policy, and if there is a question about the specificity of information which should be disclosed, consultation should be sought from legal counsel prior to release of the information.

Age Range:

The following age ranges should generally be used to report both illnesses and deaths. In press releases, the age ranges should be included in parenthesis within the text as demonstrated below.

- | | |
|-----------------------------------|------------------------------------|
| ○ Child (0-17 years of age) | ○ Older Adult (61-80 years of age) |
| ○ Adult (18-40 years of age) | ○ Elderly (81+ years of age) |
| ○ Middle age (41-60 years of age) | |

Gender: The gender of the case patient should generally be released.

Geographic information: The smallest geographical area as appropriate (i.e. needed to ensure confidentiality) should generally be released.

- 1) County (release name of county of residence)
- 2) Region - five regions will be used for the state:
 - a. Northeast (NE)
 - b. Southeast (SE)
 - c. Central
 - d. Northwest (NW)
 - e. Southwest (SW)
- 3) State (as a whole)

Ethnicity and Race: The ethnicity and race of a patient will not generally be disclosed in a press release.

Example: *A 16 year old girl from Clay County dies from suicide and her obituary is posted in the local paper and on the local funeral home's website. Because an obituary is in the public domain, children deaths are rare, and Clay County has a relatively small population, the following would generally be appropriate for release – "a female child (0-17 years of age) in Northwest Iowa died from suicide".*

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Example: *A 57 year old woman in Linn County is diagnosed with breast cancer, but she is treated and does not die. Since she survived her illness, there is no information in the public domain, such as an obituary. In addition, this diagnosis is not rare and Linn County has a relatively large population – hence the following would generally be appropriate for release – “a middle age adult (40-60 years of age) woman in Linn County was diagnosed with breast cancer”.*

In unusual situations, or when unexpected information is in the public domain, the above standardized guidelines may need to be modified. These modifications should be consistent with other sections of these guidelines and consultation with the public information officer and legal counsel may be appropriate.

V. LIMITED EXCEPTIONS WHICH AUTHORIZE RELEASE OF PERSONALLY IDENTIFIABLE INFORMATION

In addition to those disclosures of information authorized above, Iowa law also allows IDPH to disclose confidential information under the following circumstances:

- Confidential public health records and information may be shared by and between IDPH employees and local board of health and health department employees who have a need for the information in the performance of their duties. (641 IAC 175.10(2)“a” & “e”, 641 IAC 1.17(3)“a” & “b”, Iowa Code 141A.9(7)). Hence, IDPH and local health department employees may share any information necessary to effectively conduct a disease investigation.
- Confidential public health records and information may be shared with public health departments in other states or the CDC or other federal agencies when necessary for the other entity to perform their duties or as necessary to conduct the investigation. (641 IAC 175.10(2)“e”, 641 IAC 1.17(3)“d”, Iowa Code §§ 141A.9(8)). Confidential information provided to other departments retains its confidential status and shall not be re-released by the receiving entity. In general, however, CDC and other federal agencies do not receive or retain individual identifying information.

Example: *An Illinois resident is hospitalized in Davenport, Iowa, and is reported to Iowa public health officials as being ill with Lyme disease. This information, including name, address, and phone number of the resident, may be shared with Illinois public health officials (both the state and the case’s local health department) as this information is needed by them to conduct the investigation and perform their job duties.*

- Public health records and information may be shared with other state governmental entities when necessary for those entities to perform their job duties. However, this information must be kept confidential by the receiving agency. In some situations, a Data Sharing Agreement may be required. Please consult the Data Management Program Manager in these situations. (641 IAC 175.10(2)“d” & “e”, 641 IAC 1.17(3)“d”).

Example: *A city planning agency requests birth and death records, including street addresses, to conduct a population forecast for both city and public health planning. The data are required in order for them to perform their job duties. A data sharing agreement is required. The data released is only for their residents.*

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Example: *A local public health agency requests a list of children eligible for Medicaid for their county. This data will be used to confirm participants and services for entitlement programs. The data are required in order for the local public health agency to perform their job duties.*

- Public health records may be released to the subject of the record upon receipt of a written authorization for release from the subject or the subject's legal representative. (641 Iowa Administrative Code 175.12, Iowa Code §§ 141A.9(2)"a"). IDPH should exercise caution to ensure that other confidential information (i.e., reference to other ill individuals) contained in the report is redacted prior to release to the subject.
- Public health records may be released in response to a court order or subpoena. (641 IAC 175.9(2)"g", Iowa Code §§ 141A.9(2)"g"). Review shall be performed by the IDPH's legal counsel or local board of health and health department's legal counsel prior to release.
- IDPH may share personally identifiable information regarding diseases, health conditions, unusual clusters, or suspicious events that may be the cause of a public health disaster with the department of public safety, the homeland security and emergency management division of the department of public defense, and other appropriate federal, state, and local agencies and officials. (Iowa Code § 135.145(2)). The sharing of such information must be restricted to only that information necessary to prevent, control, and investigate the public health disaster. (Iowa Code § 135.145(3)).

VI. PENALTIES FOR UNAUTHORIZED RELEASE OF INFORMATION

A person who knowingly violates the confidentiality statutes and administrative rules cited above may be subject to criminal prosecution for a simple misdemeanor and may be subject to disciplinary action under IDPH or the relevant entity's personnel policies, up to and including discharge from employment. A person who releases HIV/AIDS information is subject to criminal prosecution for an aggravated misdemeanor and is subject to civil action and civil penalties, and may be subject to disciplinary action under IDPH or the relevant entity's personnel policies, up to and including discharge from employment. (Iowa Code §§ 139A.25, 141A.11).

In addition, while IDPH is not a covered entity under the Health Insurance Portability and Accountability Act of 1996 (HIPAA), local boards of health and health departments generally are covered entities, and may therefore be subject to an enforcement action under HIPAA if the local board of health or health department releases protected health information in violation of that regulation. Local boards of health and health departments should seek advice from their legal counsel to ensure their compliance with the federal law.

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VIII. QUESTIONS AND EXEMPTIONS REGARDING APPLICATION OF THE GUIDELINES

Questions regarding these guidelines and any specific circumstances may be directed to the following individuals:

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